
Handbook on *Family*



Involvement

in Early Childhood



Special

Education

Programs





Publishing Information

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Ordering Information

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A partial list of other educational resources available from the Department appears on page 53. In addition, an illustrated *Educational Resources Catalog* describing publications, videos, and other instructional media available from the Department can be obtained without charge by writing to the address given above or by calling the Sales Office at (916) 445-1260.

Notice

The guidance in *Handbook on Family Involvement in Early Childhood Special Education Programs* is not binding on local educational agencies or other entities. Except for the statutes, regulations, and court decisions that are referenced herein, the document is exemplary, and compliance with it is not mandatory. (See *Education Code* Section 33308.5.)



Prepared for publication
by CSEA members.

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Preface

The early years are the foundation for a child's healthy development and readiness for lifelong learning. For young children with disabilities, development and learning in the early years depend on the quality of early intervention services. This handbook provides information on the development and maintenance of quality programs, the statutory and regulatory requirements, and the resources available to local educational agencies to support those programs.

Background

Infant and toddler and preschool special education programs and services have changed substantially in recent years. The implementation of Senate Bill 1085 in 1993 established the Early Start inter-agency program in collaboration with the California Department of Developmental Services (DDS). This program provides early intervention services that are individually designed for infants and toddlers from birth through two years of age. Funding is provided under Part C of the Individuals with Disabilities Education Act (20 USC Section 1471 et seq.) to develop innovative ways of providing

family-focused, coordinated services that are built on existing systems.

Preschool special education programs received a boost from the federal government with the expansion of funding and eligibility categories for children with disabilities between the ages of three and five years under Title II of the Education of the Handicapped Act Amendments of 1986, Public Law 99-457 (20 USC sections 1411, 1412, 1413, and 1419). California State Law, Chapter 311 (AB 2666, Hannigan, Statutes of 1987), established program standards for all preschoolers with exceptional needs in California. Prior to enactment of this law, public schools in California were mandated to serve only preschool children requiring intensive special education and services.

Principles of Early Childhood Special Education Service Delivery

The handbooks in the Early Childhood Special Education series are based on the following principles:

- Early childhood special education programs must be child-centered.
- Programs should be family-focused.
- Programs should be culturally sensitive.

- Collaborative interagency coordination is the most efficient and effective way to provide services to families.
- Programs should provide trans-disciplinary approaches to assessment of children and delivery of services.
- Programs should provide opportunities for staff development.
- Program evaluation is a necessary component of special education programs and services.

Purpose of the Handbook

The Early Education Unit of the Special Education Division, California Department of Education, is providing staff in the field with a resource that presents quality criteria for best practices in program development, ideas, and concepts in the context of the statutory requirements for early childhood special education

HENRY DER
*Deputy Superintendent
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programs. New federal and state statutes and changed regulations and funding mechanisms have affected the provision of services for young children with disabilities. Such changes make it necessary to update and expand the *Preschool Special Education Program Handbook* (published in 1988) to include information on the infant and toddler early intervention programs.


Each handbook in the Early Childhood Special Education series describes core concepts and best practices that are based on an in-depth review of current literature, statutes, and regulations. These handbooks may be accessed on the Department's Web site.

We thank the parents and educators who contributed the ideas in this handbook to make it a valuable resource for administrators, teachers, and family members.

ALICE D. PARKER
*Director
 Special Education Division*



Message from the Authors



This *Handbook on Family Involvement in Early Childhood Special Education Programs* is written by parents of children with developmental disabilities. The children participated in a county infant development program, attended public preschools and elementary schools, and are clients of regional centers. The three families came together to work on this handbook collaboratively. The handbook is based on the following beliefs:

- The relationship between a parent and child is at the heart of parent involvement.
- Parent involvement is critical to children's success in school and in life.
- Parent-professional collaboration is the key to encouraging parent involvement.

This handbook gives service providers an understanding of what families need in order to be effective in their involvement with their children, their children's education, and the community. We also want to present some recommended practices in family-focused services.

Our knowledge is still unfolding over the years on the journey that began with the birth of our children. We all experienced the pain that comes with the loss of the "normal, healthy" baby that we had expected and prayed for, but at the same time we fell in love, heart and soul, with the baby we were given. At this point in our journey, we are beyond the shock and confusion. We are at the "all right" stage. Coping is no longer a part of daily living. Life is really okay.

In the words of Florene S. Poyadue: "Parents experiencing the appreciation stage not only accept the fact that their child has a disability (mental retardation) but that the presence of the disability is really all right."¹

It is important to make this point because one of the most difficult challenges we have as parents is overcoming society's negative view of disability. Wouldn't it be wonderful if all of society could reach the appreciation stage? The solution is relatively simple. The appreciation stage is merely a process of enjoying positive experiences with our children in settings natural to families with young children and sharing those experiences

¹ Ann P. Turnbull and others, *Cognitive Coping, Families, and Disabilities*. Baltimore: Paul H. Brooks Publishing Company, 1983, p. 103.

with others. We are asking service providers as partners in collaboration, with the very best intentions for our children, to help us open the doors to these experiences.

A recent publication by the Partnership for Family Involvement in Education cited 30 years of research that clearly showed that family involvement is critical to children's success in school and for the rest of their lives.² Congress echoes this conclusion in the reauthorized version of the Individuals with Disabilities Education Act of 1997 (IDEA '97): "Over 20 years of research and experience have demonstrated that the education of children with disabilities can be made more effective by strengthening the role of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home."³ (Appendix A outlines the regulatory requirements for family involvement in the infant/toddler programs of local educational agencies.)

To be effective primary caregivers, decision makers, teachers, role models, and managers with their children, all parents need confidence, guidance, information, and support regardless of whether or not they have a child with a disability. It just happens that those of us navigating lives in the seas of disability have an uncharted course and some choppy water to cross.

As professionals with experience in health, education, child development, speech and language development, gross and fine motor development, and vision and hearing, **you** have the knowledge of resources and services that can help **us** meet the challenges of parenting a child with a disability. We think a collaborative approach between professionals and families is the best way to help children with disabilities.

*Cindy and Gary Arstein-Kerlake
Teresa and Bob Androvich
Angela and Pat McGuire*

² Partnership for Family Involvement in Education, *America Goes Back to School*. Washington, D.C.: U.S. Department of Education, 1996.

³ Matrix Parent Network and Resource Center, "Matrix Supports Parent Participation and So Does Congress," *The Networker* (Fall 1997), 5.

The Value of *Family Involvement* and *Parent-Professional Collaboration*

The first step toward change in our education system is the increased involvement of parents and other concerned adults. Improvement cannot and will not happen without parents as partners. Greater involvement, collaboration and interaction among parents, students and schools will fuel the transformation of American education. It all begins with the choice for something better. We must all act on that choice.

—Joan Kuersten, “Parents as Partners”

Involvement by parents and professionals in the education system is one of the most significant ways to improve early intervention and preschool programs. This section discusses the benefits of parent-professional partnerships.

Family Involvement



Family involvement activities begin at home with the interactions among family members and especially between a parent and a child. Parents are lifelong teachers, continuing to educate their children long after their childhood is over. They teach by their examples and mistakes. It is hoped that they can inspire a desire for learning, encourage family values, model social skills, and guide their children toward adulthood.

Families who are involved in their children’s upbringing provide a solid foundation of values and beliefs to sustain children throughout their lives. When educational and other service agencies provide programs that build on a family’s own efforts to help their children, they are contributing to the success of the family.

Parent-Professional Teamwork and Collaboration



A *team* is defined as two or more people who collaborate to attain a goal or objective. *Collaboration* is defined as a process of problem solving by team members, each of whom contributes his or her knowledge and skills and is viewed as having equal status.¹ An effective working relationship with others requires collaboration, especially between families and professionals working together for the best interests of a child with a disability.

Unfortunately, most people are not trained in collaboration. Since 1992 public schools, in response to the needs of the business world, have begun to restructure the curriculum to include training and practice in teamwork. Unless school districts provide specific in-service training, it cannot be assumed that either parents or professionals in early intervention programs know how to practice collaboration. Such training is essential, particularly for professionals who must

work together to provide services to children and families.

Early interventionists trained in collaboration can easily be role models for parents. Collaboration centers on mutual understanding, attitudes of respect, and sharing. Attitudes are contagious. If the process of collaboration and roles are explained, parents, as invited members, can participate effectively on the collaboration team.

Table 1 represents a model of collaboration for any team. The rubric is particularly applicable for a parent-professional team because it makes no assumptions or caveats about the competencies or knowledge of the participants. Each of the defining characteristics implicitly requires respect for each team member and the ideas or information he or she brings to the process. Each team member is equally responsible for reaching goals, participating in and making decisions, sharing accountability for outcomes, and sharing resources. A collaborative process based on mutual respect and sharing encourages and enables all team members to be active and valuable members of the team.

¹Mary Beth Bruder and T. Diane Hatcher, *Transdisciplinary Teaming in the Preschool Classroom*. N.p.: Division of Child and Family Studies, Department of Pediatrics, University of Connecticut Health Center, n.d., p. 1.



Table 1. What Makes Collaboration Work

<i>Defining Characteristics</i>	<i>What Works</i>	<i>What Doesn't</i>
Mutual Goals	<ul style="list-style-type: none"> ✓ Develop a relationship with team members. ✓ Engage in small-scale efforts. ✓ Identify a shared philosophy. 	<ul style="list-style-type: none"> ✗ Engaging in a long-term commitment without having established a relationship with team members
Voluntary Participation	<ul style="list-style-type: none"> ✓ Invite the participation of key stakeholders. 	<ul style="list-style-type: none"> ✗ Working with only one or two individuals on something that will affect many
Parity Among Participants	<ul style="list-style-type: none"> ✓ Use names, not titles, when interacting. ✓ Rotate team roles (e.g. facilitator, timekeeper, recorder). 	<ul style="list-style-type: none"> ✗ Calling John Jacob Professor Jacob instead of John ✗ Reserving the role of facilitator for a select few
Shared Responsibility for Participation and Decision Making	<ul style="list-style-type: none"> ✓ Share perspectives about decisions. ✓ Brainstorm before making decisions. ✓ Clarify and identify actions agreed upon. ✓ Coordinate tasks and divide the labor according to each member's resources. 	<ul style="list-style-type: none"> ✗ Assuming that tasks must be divided equally and that each party must participate fully in each activity ✗ Assigning responsibility for decision making to one individual or party
Shared Accountability for Outcomes	<ul style="list-style-type: none"> ✓ Acknowledge risks and potential for failure. ✓ Celebrate success together. ✓ Embrace failures together, adopting a mindset of learning from failures. 	<ul style="list-style-type: none"> ✗ Trying to determine whom to blame ✗ Giving awards to individuals for team efforts
Shared Resources	<ul style="list-style-type: none"> ✓ Identify respective resources. ✓ Establish mutual goals. ✓ Highlight the benefits of sharing. ✓ Make decisions jointly about resource allocation. 	<ul style="list-style-type: none"> ✗ Protecting resources rather than revealing them ✗ Having no mutual goals and disparate benefits ✗ Using one's own resources after depleting others' resources

Source: Mary Beth Bruder, Division of Child and Family Services, University of Connecticut Health Center, DEC Conference, San Diego, California, December 12, 1993. Reprinted in Ann Carr, Anne Kuschner, and John Gunnarson, "Team Building," in *Building Success for All Children: Walking the Talk*. Workshop Binder, Year One. Rohnert Park: California Institute on Human Services, Sonoma State University, 1995, pp. 3–4.

The following narrative describes an actual experience of collaboration between a family and a service provider. Although the provider is from the medical field, the narrative shows the characteristics of successful collaboration: mutual respect and trust. This approach may be used by any service provider employed by any agency working with families.

Collaboration in Action

Voluntary Participation

At my pediatrician's suggestion, we voluntarily made an appointment with a geneticist two weeks after my baby Sara was born. We chose to go on this fact-finding mission. It gave us ownership of our part of the collaboration and of the outcome. It naturally helped commit us to the partnership. Our purpose in going was to try to find out for sure if anything was wrong with Sara and, if so, where we were to go from here.

Parity Among Participants

The geneticist showed his respect by promptly greeting us himself and introducing himself by his first name.

Mutual Goals

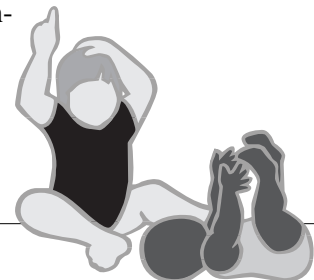
He showed us he was on our side, a part of the team, by sitting beside us. He demonstrated family focus by asking about our other daughter, Anna. He established a common ground, parenting, when he told us about his efforts to understand his son's feelings. His son was saying "I hate you" whenever something didn't go his way. We exchanged similar experiences about Anna.

Shared Responsibility for Participation

During his assessment, Dr. Smith² assumed nothing and encouraged us to tell our whole story while he listened carefully. We told him about the referral from the pediatrician and the initial inconclusive results of the genetic testing. He asked us about life with Sara. What was her daily schedule like? What were her likes and dislikes? Did she cry a lot? Was I nursing? How much did she eat? Was she still waking up at night? As we answered his questions, he listened with empathy as though he'd heard our story before and encouraged us to expand on our responses. He enabled us to be an important part of the assessment.

The way in which he conducted the assessment modeled unconditional love and **acceptance**. His words and actions demonstrated how much he valued and enjoyed my baby and **validated** our own positive feelings about Sara and her **future**.

After appreciating her healthy appearance, weight gain, and the developmental progress she'd made, he showed us how far behind she was developmentally from other three-month-old babies. He confirmed his assessments with the developmental specialist, carrying her next door and sharing her like a treasure. **Consulting** with another expert helped us to accept his assessment.



²The name of the service provider has been changed.

Collaboration in Action (Continued)

Shared Accountability for Outcomes

Now it was our turn to ask: “Would she grow out of this? Would she ever be normal?”

Dr. Smith shook his head and said no, without any lengthy explanation or speculation. His answer was followed by a question for us: “What are your goals for Sara?” My husband said something about wanting her to be a contributing member of society, and I said I just wanted her to be happy.

Our next question was “Where do we go from here?”

Shared Resources

Options for pursuing a diagnosis were discussed. He explained that diagnosis is arrived at by a process of elimination and then described the various kinds of tests. We asked questions. He shared his thoughts on the alternatives and offered us a stack of books from his office so we could do some of our own research. He also informed us about support services from the regional center and the county office of education’s Infant Development Program. He made it clear that there were no quick, easy answers and that use of the support services was voluntary.

Shared Responsibility for Participation and Decision Making

Before we left his office, we had decided on a course of action. Dr. Smith concurred with our decisions, and as we left the office, my husband and I felt as though we were respected members of a team who had provided valuable information for our daughter’s assessment and had made informed decisions in planning for her future. On the way home we both cried, acknowledging that our Sara would never be normal. But we moved forward, loving our daughter and talking about following up on our newly made plans.

Parity Among Participants

Dr. Smith let us know that he was available any time to answer questions by phone or that we could make another appointment to meet with him to discuss any questions.

Mutual Goals

We signed a consent form for Dr. Smith to continuing testing in pursuit of a diagnosis.





Parent Involvement in Professional Teams

According to the California Interagency Coordinating Council on Early Intervention, as stated in *Family Support Guidelines for Effective Practice*, “Every agency should ensure that all agency staff receive ongoing training and supervision in family-centered service delivery.”³

Personnel development that includes parents as a part of the professional team may be accomplished in the following ways:⁴

- Provide training in the philosophy and strategies of parent-professional collaboration.
- Have parents and professionals conduct training in collaboration.
- Use specialized consultants and program assistants who are parents of children who are disabled or at risk of disability.
- Hire qualified staff members who are also parents of children who are disabled or at risk of disability.

Parents as professionals can be a valuable addition to any early intervention team or preschool program. Adding a parent to a professional team offers some unique benefits because the parent:

- Provides a readily available parent perspective

- Lends credence to the organization as a family-focused agency
- Helps to bridge the gap between parents and professionals
- Helps model parent-professional teamwork.
- Improves the communication between parents and professionals
- Provides information about the activities, resources, and needs of parents
- Validates the provider’s commitment to parent involvement

In some early intervention programs, parents and professionals from the Family Resource Center are used as a part of the intake team helping to elicit a family’s concerns, resources, and priorities. Because of the parents’ personal experiences with the assessment process, team members truly understand a family’s emotional state and confusion about the service delivery system and that families have difficulty in verbalizing their needs and understanding their rights. In turn families more readily trust and open up to a person who has shared the experience of having a child with a disability. Parents can also make wonderful volunteers in the classroom. A parent’s presence can provide a welcoming, understanding atmosphere that facilitates family-to-school communication, encourages parent involvement, and gives families confidence in their choice of early intervention programs or preschools.


³Linda Brekken, “Personnel Qualifications and Personnel Development,” in *Family Support Guidelines for Effective Practice*. Sacramento: California Department of Developmental Services, Interagency Coordinating Council, Family Support Services Workgroup, 1994, p. 12.

⁴Ibid.

Entry into the Early Intervention Program

Short of having your child die, there is nothing more devastating to a parent than to be told that there is something “the matter” with your child; your child is “not normal.” . . . All parents have strong feelings about their children. When they believe there is something wrong with the child, then some of those feelings can be pain, anger, guilt, and anxiety.

— Lucia Milburn, “A Parent’s Perspective: Assessment and Intervention,” *Infant Development Association Newsletter*

An illustration showing a parent and a child. The parent is on the left, wearing a dark tank top and light pants, with their arms raised in a gesture of surprise or joy. The child is on the right, wearing a dark tank top and light pants, with their hands clasped together in front of their face, appearing to be crying or overwhelmed. The illustration is rendered in a simple, stylized manner with black outlines and flat colors.

The initial interaction that occurs between parents and professionals is an important event. Parents often feel very vulnerable when they begin to use early intervention services, and sometimes strong feelings are close to the surface. Professionals should be aware of this and respect those feelings. As one parent wrote:

The foremost task of any parent is to develop a deeply loving, mutually satisfying, nurturing relationship with his or her child—the total child. This is important for the sake of both the child and the parent. Being a parent is primarily about being in a relationship with their child. The characteristics of such a relationship are:

1. The parent must have a positive view of the child. She must accept and be satisfied with, even celebrate, the child for who he is.
2. The parent must derive pleasure from the relationship with the child.
3. The parent must feel competent in the relationship.⁵

⁵ Lucia Milburn, “A Partner’s Perspective: Assessment and Intervention,” *Infant Development Association Newsletter* (Spring 1991), 1–2.

Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof, or many. A family can be as temporary as a few weeks or as permanent as forever. We become a part of a family by birth, adoption, marriage, or from a desire for mutual support. . . . A family is a culture unto itself, with different values and unique ways of realizing its dreams; together our families become the source of our rich cultural heritage and spiritual diversity. . . . Our families create neighborhoods, communities, states, and nations.

— From *Family Support Guidelines for Effective Practice: Recommendations of the California Interagency Coordinating Council on Early Intervention*

Family involvement is a belief in the value of partnership that is shared by service providers and families. The intake process is a difficult time for families as they are asked to identify and address their child's deficits. Several features characterize agencies that encourage family involvement. When families are welcomed into systems with these features, everyone can benefit and grow in the process. The following sections identify those features.

Family-Centered Focus



Each family has varying needs when beginning to use services. Some families are aware of the services needed and are ready to enter the infant or preschool program as soon as possible. Some can identify their child's needs or disability but lack the information to request specific services. Some have other family needs that must be addressed before they

can use specific services. All families need to have their concerns and priorities acknowledged and addressed throughout the process. The California Interagency Coordinating Council on Early Intervention states: "Services and support will best meet the needs of families by focusing on the entire family and building on the family's strengths, respecting cultural preferences, values, and unique lifestyles."⁶

Coordinated Processes



The process of intake and assessment may be emotionally taxing and time-consuming for families.

When no relationships have been established between the parent and agency staff, requesting personal information from the family may be uncomfortable. When the process is not coordinated, these requests may be repeated numerous times as a family is referred to different agencies at initial intake and during transition to a new program. Repeated assessments place undue stress on a

⁶ *Family Support Guidelines for Effective Practice: Recommendations of the California Interagency Coordinating Council on Early Intervention*. Sacramento: California Department of Developmental Services, 1994, p. 22.

family because the focus often must be on the child's deficits rather than on the parent-child relationship. Although the assessment process is necessary, the family's best interests are served when this process is coordinated, with agencies collaborating to share information as needed and permitted by the family. Without coordination, there may be a loss or delay of valuable services.

Intake and assessment is a process that involves many steps. When agencies work together to coordinate this process, the family's access to services is easier. Service coordinators are responsible for providing consistent and accurate information. The service coordinator may immediately refer a new family to a Family Resource Center. The parent-professional staff of the Family Resource Center can assist the family through the initial individualized family service plan (IFSP) process and establish an ongoing relationship with the family.

Proactive Strategies



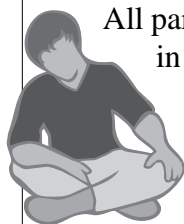
Parents need to receive complete and clear information about the services they will receive. Service delivery may appear to be a complex process to families. The best practice is for service providers to give families the full range of available information, resources, and services.

A study conducted by Parents Helping Parents (PHP) indicated that as information and resources to families increased, their need for outside support decreased. Families in the study were given information on available community resources, parent and child rights, particular disabilities, and financial supports. In addition, they were connected with other families who had been through the process.

When parents and guardians are given information and resources, they

become empowered to identify and seek out resources and supports needed for their child and family. Having the same information that is available to professionals helps them become equal participants on the team that is working in a positive and productive direction for the child and family. One way to ensure that families have all the information they need is to provide them with a resource binder that can be referred to and updated over time. Ideas for establishing a friendly environment in the child care center are provided in Appendix B.

Maximum Parent Involvement



All parents or guardians are involved in the intake and assessment process to some degree.

Parents' concerns, priorities, and needs must not only be elicited but also be acted upon as the building blocks for the IFSP. Parents have a right to know all the service options for their child and be a part of the decision to enter their child in the early intervention program.

Because parents are the experts on their baby's behavior, they are an important source of information during the evaluation and assessment process. They know the child's likes and dislikes, favorite toys, and feeding and sleeping schedule. It is important to remember that although parents are experts on their baby, they may not be experts in the jargon of early intervention. Asking open-ended questions, such as "Tell me about the sounds your baby makes" or "Tell me more about how you feed your baby," will help elicit the information that is needed by professionals. Some cultures do not encourage parent involvement in the education of a child. Such cultural values must be respected while eliciting information from the parents.

There is considerable variability as to the role and degree of control families want to assume during the evaluation and assessment process. Even if parents choose to do no more than observe, the process of engaging them as “active” observers is still a step in figuring out the family’s desired outcome for the child. If the family doesn’t feel involved, nothing will change.

—From Carol Berman, “Family-directed Evaluation and Assessment under the Individuals with Disabilities Education Act (IDEA): Lessons Learned from Experiences of Programs and Parents,” *Zero to Three*

Maximum parent involvement does not imply that the parent becomes the interventionist. “A parent must refuse to become just a teacher, therapist or service coordinator in order to be true to their primary task as a parent—to nurture the whole child in the context of a loving, deeply satisfying relationship based on acceptance, respect and joy.”⁷ Each parent determines his or her own level of involvement according to family needs and other commitments and responsibilities.

Parent-to-Parent Interactions



Parents look to others in similar situations to be a source of strength and information. Every service provider from the medical field, therapists, social workers, teachers, and others must believe in the power of connections with others. From the very beginning of the parent’s involvement in the early intervention program, the agencies involved can play a major role in supporting parent-to-parent connections by providing support groups, social groups, playgroups, and educational activities, depending on the needs expressed by the families.

Timely Delivery of Services



Parents need systems that can respond quickly to the rapidly changing needs of their young children. It is important to ensure that agency processes and paperwork do not delay services and cause frustration, anger, or stress for the families. When agencies collaborate on establishing a child’s eligibility for services, time is saved and the service systems can be primarily concerned with addressing the needs of the child and family. The parent can remain free to concentrate on maintaining the health of the family .

Once needed services have begun, parents can move forward in a productive and healthy way. Parents will feel a sense of normalcy and wellness throughout the collaborative process. Their focus shifts to their child’s growth and development and to their dreams for the future.

The following activities help increase parent involvement in obtaining early intervention services:

1. Assisting with parent-to-parent connections
2. Establishing a multiagency approach to intake and assessment when initiating services and during transitions

⁷ Lucia Milburn, “A Parent’s Perspective: Assessment and Intervention,” *Infant Development Association Newsletter* (Spring 1991), 7.

3. Supporting and collaborating with Family Resource Centers and other parent support groups and referring parents to them
4. Providing frequent, community-based parent education programs based on the needs of families
5. Planning collaborative workshops attended by parents and professionals
6. Assembling information packages on services, specific disabilities, and

current information on community resources

7. Encouraging parent participation on advisory committees, boards of directors, and program planning and evaluation teams
8. Providing professional support and advice to parent support groups
9. Participating in community outreach activities



Family Involvement Activities in Early Intervention Programs

Practitioners who work directly with very young children and their families need supportive collegial and supervisory relationships to serve children and families effectively. [What is necessary] for programs to flourish is a management strategy that is committed to modeling strong, mutually respectful relationships—relationships between parents and children, relationships between families and staff, relationships among participating families, and relationships among staff and with other community organizations and service providers.

—From Keith Lally, “Early Head Start: The First Two Years,” *Zero to Three*



As a child grows older, gains more skills, and needs less care, the parents are better able to participate in activities beyond those of meeting essential needs. At this stage, parents may need the opportunity to talk with other parents of children with disabilities. Family playgroups or parent education coffee hours (with child care provided) are informal support activities that can promote both parent involvement and interaction with other parents.

As early as possible, parents need to develop natural support for their children—that is, develop relationships with those in their neighborhood and community. Parents can do this by participating with their children alongside parents of children without disabilities in a variety of stimulating parent-child activities. Early intervention programs may facilitate this kind of interaction by sponsoring community activities for parents and toddlers, such as a music program or playgroup; or professionals can partner with local parks and recreation departments, encouraging parents to participate in parent-child programs and providing information about and support for children with disabilities.

To ensure success, staff must include parents when planning family involvement activities. Conduct a needs assessment to determine the types and locations of activities desired and the best times for scheduling the events. In addition, evaluations conducted after planned events, at mid-year, and at year end are useful in assessing activities and making changes to serve families better.

Community-Based Services



When services are centered in the community, families benefit in many ways. Each community is unique, and child and family needs are different at each developmental step. It is important to support families in maintaining connections in their established communities when they have a child with special needs. Children can learn in natural environments—the communities where they live—and receive support from community connections. Services for families should be delivered in a way that promotes and builds on support from the community.

Community connections include extended family, church programs, neighborhood schools, playgroups, co-ops for child care, recreational programs, and local children’s organizations. Family members or siblings may already be involved in

community activities. Individual families benefit from this connection as well as the community as a whole.

Collaborative Process



With collaboration as a basic value of all providers, the family can quickly form the relationships necessary to obtain appropriate services for the child. These relationships make it easier for individual services and supports to come together.

Multiagency teams are a good example of the collaborative process in action. The parent or guardian is an important member of the team. Other team members may include another parent (possibly from the local Family Resource Center), representatives from agencies providing services, members of community groups, extended family members, child care providers, or anyone else who is needed to complete the picture. Team members meet together to form a common plan and produce a single report, make recommendations, and complete an IFSP based on the needs identified by the team. Some activities may be completed by individuals, while others, such as assessments, may be conducted by the team. When this type of plan is developed, everyone benefits. All individuals become more capable, competent, and responsible as a result of their involvement in a collaborative team.



Administrators may plan family involvement activities that are appropriate for families of children ages birth to five years. One benefit of combining family involvement activities for infants, toddlers, and preschoolers is that parents of

younger children meet parents of older children and develop friendships that provide support. Another benefit is that expanding the age range to include others increases the chance for success of the activity. Table 2 shows family involve-

Table 2. Family Involvement Activities

School- or Center-Based Activities

- Parent support groups
- Parent-professional training
- Sign language classes
- Parent advisory committees
- Involvement in community activities, such as:
 - Parent-toddler gym
 - Mommy and Me swimming
 - Parent-tot music time
 - Parent-toddler creative playtime
- Playgroups
- Parents’ Night Out—an opportunity for parent education, such as presentations or demonstrations of various stimulating homemade toys or therapy approaches, with on-site child care provided by staff

Social Activities

- Family picnics and potlucks
- “Second cup of coffee”—drop-in or scheduled coffee hour
- Mom’s Night Out
- Dad’s Night Out
- Quarterly family gatherings
- Play day in the park

Celebrations and Special Events

- Annual reunion—evening or weekend
- Holiday celebrations
- Volunteer appreciation
- Beginning and end-of-year picnics

Community Events

- Week of the Young Child
- Information fairs
- Special Olympics
- Team presentations to medical community
- Ability awareness days
- Multicultural events
- Stand for Children Day

ment activities for parents of both infant and preschool children with disabilities.

At times professionals express concern and frustration when parents do not respond to repeated invitations to family involvement activities. School and program staff may not realize that, if there is no extended family in the area, parents may feel that they are the only ones who can provide their baby's care. Even if there are two parents working full time, the chances are that one parent spends more time taking care of their infant's basic needs. This primary care provider may become isolated from spending so much time taking care of a child with a disability. Parents often abandon social activities, interests, and hobbies in caring for a child with a disability.

Parents may not be able to do more than attend scheduled meetings and appointments. They may not even find the time to work on the activity cards left by the teacher the week before. Although

parents may not get involved in all the activities, they do appreciate the support and encouragement of professionals. Home visits by professionals or visits to the center may be the only opportunity parents have to discuss their baby's progress and talk about how they are managing as a family.

Helping a family member to take care of himself or herself may be a prerequisite to further participation in family involvement activities. Therefore, respite services are invaluable, as are purely social activities unrelated to any issues of disability. For example, one program, in collaboration with the local Family Resource Center, invited students from a massage certification program to provide an evening of massage sessions for one of their monthly Mom's Night Out meetings. A fathers group is another important form of support to parents. (See Appendix C, "Where's Daddy?")



The *Transition* from an Early Intervention Program to Preschool

In building a vision of their child's future, parents frequently dream that their child has normal opportunities. For me and my daughter, there was no better place to start than the neighborhood parent-participation preschool. This is where parent participation and parent education are an integral part of the program; where all mothers are struggling to figure out if their child is in a normal state of development; where teaching social skills is a natural part of everyday interaction with the kids; where baby-sitting co-ops form; where friendships and natural supports are built every day; and where exploration, discovery, and development thrive. But, best of all, it's where a family with a child with a disability can be a normal part of their community.

—Cindy Arstein-Kerslake, Parent

At least six months before a child's third birthday, parents need to consider preschool options. The service coordinator or other early intervention staff member with whom they have developed a trusting relationship provides advice, presents the options, leads parents in planning, and helps them complete the paper work. When the transition individualized education program (IEP) emerges from this process, parents can be confident and prepared members of their child's IEP transition team.



Explore Preschool Options

All parents want the best for their children. Many families with children entering preschool spend time observing preschools to select the one that best meets their child's and family's needs. A tool to help parents in identifying an appropriate program is provided in "Ten Signs of a Great Preschool" (see Appendix D). Families whose children may or may not qualify for special education at age three and are leaving an early intervention program undergo the same process. The only difference is the amount and type of information the parent will need to make meaningful, informed observations and decisions. Families need to see and understand various types of special education classrooms and regular early childhood education classrooms.

They have a legal right to be informed of all placement options for their child. Providing parents a mini-course in best practices in early childhood education that includes special education and a checklist of standards from which they can make their assessments will support them in making informed decisions for their child. After observing the alternatives, they may need to meet with the transition team to discuss available options to meet their child's needs. Once the placement decision has been made, the early intervention staff can help the parents and child meet the preschool staff.

Create a Vision



In deciding which preschool environment can meet their child's needs, parents need help articulating where they want to see their child in the world. Often they have hopes from the day their child was born and, at this point, their dreams need to be expressed aloud. Parents may need some help creating a vision by verbalizing and describing it.

Creating a vision has been used in the education system by schools embarking on restructuring and new schools before they begin design and construction.

The process brings together parents and professionals in building dreams of a better school system for their children. The group decides on goals and objectives that coincide with the dreams and examines the resources and options that can make these dreams a reality.

This same kind of process, on a smaller scale, helps parents ask themselves the following questions:

- What do we want for our children academically, socially, physically, and emotionally?
- What kind of support in the school, neighborhood, and community is needed to make these dreams a reality?
- What kinds of extracurricular activities will support and promote these goals?
- What are the preschool options that support and promote these goals?

A group of parents and professionals working together to create a vision can help answer these questions and at the same time provide a positive outlook for the future; it is a wonderful exercise in team building and collaboration. It serves to educate, inspire, and open new doors for everyone involved. Most immediately, it gives parents and professionals an idea of directions to pursue in determining preschool services.

Parents' Vision for Their Children

- We want our children to be happy.
- We want our children to progress developmentally.
- We want our children to be safe and free from ridicule.
- We want our children to have appropriate social skills.
- We want our children to have friends who love them for who they are.
- We want our children to be invited to birthday parties.
- We want our children to feel loved and accepted by our community.
- We want our children to reach their greatest potential.
- We want our children to be involved in fun after-school activities with neighborhood friends.
- We want our children to have similar opportunities as their same-age peers and siblings have.

Plan the Transition



Informed families who understand the preschool program and participate in choosing a preschool and service provider are likely to be involved preschool parents.

Families who were not involved in selecting the preschool are less likely to be committed to the choice and may not want to be involved in the preschool program's activities for families.

Hosting a transition fair is a strategy used by many school districts to provide information on resources, including transition and preschool options, to more than one family at a time. Representatives from local school districts, the local resource and referral agency, Head Start, child care programs, various types of preschools, and any agency that offers an early childhood education program could present information about their preschools at a central location. This type of event requires inter-agency collaboration in putting on the fair and provides a valuable educational experience for parents and staff alike. It also helps parents to review their placement options and select preschools for visits.

The Individuals with Disabilities Education Act of 1997 (IDEA '97), with its emphasis on the least restrictive environment, provides funding and program policies that allow for a child's placement with typically developing peers. Family and staff should consider the regular early childhood settings in their community and design the necessary adaptations to accommodate the child's special needs.

Parents may wish to visit various preschools. A professional or a trained parent leads or coordinates the visit and

provides insight into what parents are observing.

The multidisciplinary transition team, which includes the parents, determines that the child is eligible for services; an IEP is developed; and an appropriate program, including placement and necessary support and adaptations, is selected that meets the requirements for achieving the IEP goals. The parent provides suggestions and is an integral member of the team.

Preschool teachers may want to visit the infant program to see how the child behaves and works in the classroom setting. Teachers armed with this information can provide a smoother transition between the infant and preschool programs.

Say Good-Bye



It is important to have a time for children and families to say good-bye to those who have worked with them in the program. Celebrations help ease the transition

process. Families have the opportunity to thank staff for their friendship and support. The staff, having developed a relationship with the family, can acknowledge that relationship. Parents and professionals together are able to stop and take time to recognize the accomplishments of the children. As a team, they can appreciate the results of their hard work in supporting the growth of the children.

A celebration is held to acknowledge everyone's work, accomplishments, and friendships. Parents are invited to attend a farewell party on the child's last day of the infant program.

Parent Education

The goal is not an end—a parent program—but a process toward satisfied and self-actualizing parents and effective home-school relationships. The ultimate goal is one which is shared by both the parents and the school: . . . people who are independent, self-sufficient, and participatory members in their own community.

—From Roslyn Rosen and others,
Parent Education Resource Manual



Before designing a parent education program, the professionals involved need to examine the goals, expectations, and priorities of the early childhood special education program as a whole to consider their impact on the parent education program.

As children with special needs leave the infant or preschool program, their parents also need to leave with skills that will enable them to raise their children with understanding and effectively participate in their children's education and services. Parent education provides a foundation for the child's future.

The *Parent Education Resource Manual* (Rosen and others 1982) provides guidelines for developing a parent education program suitable for any parent group. They may be used to build parent education programs that are truly responsive to parents' needs and that will result in parents better prepared for parental responsibilities beyond the world of early intervention services.

The following guidelines may help administrators to develop an effective parent education program:

- Define the audience.
- Assess the audience's needs and experiences.

- Involve parents in the planning process.
- Solicit and select topics relevant to parents.
- Select appropriate delivery models based on sound adult learning theory.
- Recruit experts and gather other resources.
- Schedule joint parent-professional staff development opportunities at times convenient for both staff and families.
- Design an evaluation process and mechanisms for incorporating evaluation data into the program.
- Plan an ongoing series of activities designed to meet the objectives of the parent education program.

Define the Audience



Parents of children with disabilities have their own personality, cultural background, lifestyle, and educational background, which may include training in a professional field. Each parent's level of acceptance of the child's disability will vary as will the parent's comfort level with professionals and other parents.

Assess Needs and Experiences



It is important to discover each parent's needs and experiences

without making assumptions. For example, a parent may or may not have knowledge about child development or disabilities and may or may not be grieving. Generally, with parents new to the world of special education, an informal style of questioning and presentation is most effective. "Tell me about your child" is warmer and less intimidating than "What is your child's diagnosis?" or "Why was your family referred for early intervention?" Usually, once parents feel comfortable to speak freely, they will do so.

Involve Parents in the Planning Process



Parents new to special education may not know what they want or need or what questions to ask.

However, they may still have needs and questions. Ask parents to assist in planning. Discuss with them:

- How they want information presented
- What they want to learn

A good idea is to invite parents of children who have graduated from the program to a meeting to share with current parents what they liked about the program or wished they had known five years earlier.



Solicit and Select Topics Relevant to Parents



Preschool or kindergarten survival skills may be a topic of great interest. Parents want to know what will be expected of their children at school and whether their own expectations are reasonable. This information may help in setting goals at an IFSP or IEP meeting or as an introduction to the concept of least restrictive environments.

Topics for Parent Education

- Special education terminology
- Parenting skills and concepts
- Transitions
- Child development
- Legal rights under the IDEA and the concept of least restrictive environment
- Preparing for independence
- Behavior management
- Positive discipline
- Sibling relationships
- Understanding disability
- Community resources
- Summer/vacation activities
- Traveling with children
- Computer technology
- Toys: buying, making, and adapting
- Taking care of yourself
- Characteristics of quality programs
- Storytelling
- Finding time with your spouse
- Cooking for or with children
- Finding a pediatrician or dentist
- Useful catalogs/resources
- Nutrition recommendations
- Brain development
- Early literacy

Select Appropriate Delivery Models



Typical sites for parent education classes are the classroom, a clinic, or a home. Classes at a popular social spot in town, such as a coffeehouse, restaurant, clubhouse, or park, may be more inviting to parents burned out on institutional settings such as schools and hospitals. Many sites are open at hours that will accommodate a parent group or have rooms available for groups of various sizes. Usually the cost is not prohibitive, and parents who have a guilt-free reason to leave their children and possibly expend precious respite hours may find the class an opportunity to treat themselves to something worthwhile. Some parents who have retreated from community life in their efforts to cope with the new situation of having a child with a disability may be drawn out in this way.

Another alternative is to hold meetings at a zoo or community play place, where children may be accompanied by staff or child care providers if necessary, and education may be meshed with fun. Consider providing transportation, either to bring the parents to the program or the program to the parents. When bus transportation is furnished for a field trip, parent education can be successfully provided during the ride to and from the event. Additionally, meetings in the community provide an opportunity for some good public relations exposure for your program and for families and people with disabilities in general.

Parent participation is one of the most powerful methods of parent education. Parents may attend every seminar offered, read the latest bestsellers in child development, and consult with as many experts as they can reasonably reach, but the information does not become real until they apply it. Opportunities for parent

Non-participation should not be construed as lack of the parents' interest or concern. . . . Rather, the program delivery method should be analyzed to determine whether it meets the parents' needs.

—From Roslyn Rosen and others, *Parent Education Resource Manual*

participation are abundant. Parents can be involved in implementing parts of their children's educational programs by doing the following: work on exercises at home or in a group, plan activities for the children, host or assist with field trips, make adaptive equipment, or prepare materials for the school or for home use. Participation on boards and advisory committees is immensely educational; other committee members are usually glad to answer a newcomer's questions.

Some programs have used parents as transition coordinators. With guidance from early intervention staff, parents research and visit preschools, apply for admission if necessary, develop an IEP, select an optimal placement, and follow up with the preschool chosen. This type of experience builds parents' confidence and enhances parent-professional relationships that are built on mutual respect and shared knowledge. Parents learn to question, to trust what they know about their children, and to know that their opinion is valued.

Recruit Experts and Gather Other Resources



The early intervention program does not need to be the sole source of information and education for parents of children with disabilities. Community resources are also available, such as other agencies, service organizations, and regular education early childhood teachers. All parents of children with

disabilities share similar concerns and will benefit from parent education programs that are available in the general community. Shared training also provides an opportunity for parents to talk about disabilities and inclusion.

Provide Staff Development Opportunities



Invite currently and previously enrolled parents to assist with staff development training. Angela McGuire described her participation in training:

I had the opportunity to be part of a panel of parents interviewed for the benefit of an audience of early intervention staff at a mid-year in-service. My family had just moved to California from Indiana. I don't think we had even begun receiving services yet. The staff was interested in finding out what programs in other states were doing; I just loved talking about my baby girl. Additionally, I made some valuable early contacts with professionals in the district. It was, I think, a valuable experience for all of us.

Consider visiting other early intervention programs. Many exemplary programs welcome visitors. The SEEDS Project ([916] 228-2379) at the Sacramento County Office of Special Education, under the direction of the California Department of Education, has established visitation sites throughout the state.

There is also a wealth of knowledge to be gained from experts in the field of

early childhood education. Presenters provide workshops, lectures, and seminars on a variety of topics, from working with parents to the importance of storytelling and song in the education of the very young child. Often, training sessions or presentations are sponsored by local community agencies or groups such as the resource and referral agency or the local chapter of the Association for the Education of Young Children (AEYC).

Training for parents and professionals on consecutive days may be a cost-effective way to stretch training dollars. An evening session for parents allows a special speaker to address a topic of interest to both staff and parents. Presentations may also be opened to the general public to educate the community about early childhood issues and the importance of early intervention services. Staff development should be scheduled at times convenient for staff and families.

Design an Evaluation Process as Part of the Program



The purpose of evaluation is to find out whether the parent education program is delivering correct, useful information and training to parents and to redesign the program as needed. A parent satisfaction

survey may not provide the kind of information that is needed. Evaluation takes many forms: records of attendance at parent education events, personal contact with individual parents to assess understanding, or a mini-quiz or survey following presentations. It is important to pass on the information collected, in a tangible form, to the parent-professional team responsible for planning future parent education opportunities.

Plan Activities to Meet Objectives of the Parent Education Program



The educational needs of parents change over time. Parents new to the program are being bombarded with meetings, forms, specialists, and concerned friends and relatives. They may need definitions, explanations of diagnoses and procedures, coping skills, or skills for getting through the day with their newborn. Later, parents will be ready for broader planning and looking to the future. They may want information on disability rights, national organizations, or advocacy training. However, parents will be at varying stages of development in any program at any time. Therefore, workshops that meet the needs of parents with a variety of interests should be offered repeatedly and concurrently.



Support Groups

The first time I talked to another parent of a child with a disability, I wasn't looking for a shoulder to cry on; a caring, listening ear; a confidant with whom I could discuss my greatest fears; or a friend who would truly understand my experience. All I wanted was some information about the syndrome that my baby might have. Instead, what I got was probably the most positive, helpful experience I'd had since my baby was born. It was a truly freeing experience to know I wasn't alone. Someone else had been through the same things I'd been through; my feelings and thoughts weren't irrational but normal for my situation, and someone else was facing the same challenges I faced.

—Cindy Arstein-Kerslake, Parent

Families having a child with a disability need help in coping with their feelings and their relationships with other family members. Support groups for parents and siblings are available to help families.

Parent Support Groups



The need to connect with other parents is a very natural one when a child is born with or without disabilities. Parents face many new challenges as they begin the process of raising their child.

Parent support groups are a significant source of parent-to-parent support. The primary purpose is to provide parents a chance to share common experiences and concerns, share their joys and successes, and learn together.

Groups vary in size and structure. Typically, one or two persons with an interest in helping others start a group. Those who have “been there” and are handling the situation in a positive, constructive manner are likely candidates to start the group. They have a willingness to work hard and help others. Professionals from an agency often are instrumental in the formation of a parent support group.

Parents need to be included in this process and be group facilitators.

When professionals partner with parent groups, they demonstrate the value of parent-to-parent connections and model collaboration.⁸ (Additional information about parent support groups is provided in Appendix H.) Family Resource Centers provide support to parent groups through leadership training, newsletters and mailings, and assistance in finding speakers or a space to meet.

The connections in parent support groups can be very powerful for families in the process of working hard to pave a path for their family. Having the right tools and help along the way makes the journey an enriching and enjoyable experience.

Florene Stewart Poyadue, founder of Parents Helping Parents, San Jose, California, speaks with understanding about the value of parent-to-parent support.

Strategies for coping with all of the various aspects of family life are as individualized as the life events that we each experience every day. Sometimes our coping responses are behavioral—we count to 10, we go for a long walk, we scream and shout. Sometimes our coping responses are cognitive in nature. We think about a situation in a way that will enhance our sense of well-being. We may compare our own situation to someone else's and feel better that we have our set of circumstances to deal with rather than another's; or perhaps we look ahead to someone further along in life's journey and feel a sense of hope about our own future. Considering that there may be positive benefits to an event may make an otherwise stressful situation seem less so. Sometimes simply gathering information so that a sense of

mastery or control over a situation becomes possible is helpful. Working to understand why an event has occurred and what it may mean is another way of coping cognitively with the adventures, both easy and difficult, that life sends our way. The use of humor often facilitates the successful resolution of a difficult situation and reduces stress. At Parents Helping Parents (PHP), a parent-directed family resource center in San Jose, parents of children who have special needs are provided with many opportunities to enhance and utilize their own style of cognitive coping.

To families who are meeting the challenges of a disability within the family, PHP provides the opportunity to grow, to be realistic, and to still hold on to all of the positive thinking and hope that they create for themselves. Committed to the right of children to achieve their full potential and to receive coordinated, community-based health care, education, social, and legal services with respect and dignity, through family and professional empowerment, PHP began providing emotional and informational support to families in 1976.⁹

Sibling Support



Planning a program for sibling support has to start with parent education. If parents receive information on how to resolve issues that arise in the family when children are young, siblings may not require more direct support in the future. Parents preoccupied with appointments, meetings, or their own emotions may not realize that others in the family are feeling neglected, anxious, or angry. Education may be as simple as advising parents to set aside time alone with a sibling who

⁸ Florene Stewart Poyadue, Parents Helping Parents Workshop at the National Down Syndrome Congress Convention, Anaheim, Calif., August 1993.

⁹ Ann P. Turnbull and others, *Cognitive Coping, Families, and Disabilities*. Baltimore: Paul H. Brookes Publishing Company, 1983, pp. 95–96.

When we have a child with extraordinary needs, our other children also have extraordinary needs. They need extra support to live with things they can't understand and information and reassurance about their own physical and emotional health. They need us to listen especially carefully to their worries and concerns and provide clear guidelines about what they are responsible for and what they are not. They deserve acknowledgment of their contradictory feelings and help in sorting out their dilemmas. They need explicit appreciation for their sacrifices and contributions.

—From Barbara Gill, *Changed by a Child*

may have feelings of abandonment because the parent is busy with the therapy needs of a family member. Encourage parents to keep open lines of communication with their children and let them know that they can expect a range of emotions to be expressed.

Parenting children of different abilities is a constant balancing act. Parents may ask:

- How much involvement is too much?
- How can time for each child be allocated fairly?

If the siblings are old enough, parents may want to invite them to assist in caring for the infant or toddler with a disability, just as the siblings of any other young child participate in his or her care. Encourage parents to monitor their own behavior; parents may expect siblings to take on more responsibility than is reasonable for self-care, chores, or even the behavior and well-being of the child with the disability. In addition to spending special time alone with each child, parents may encourage younger siblings to participate in the early intervention classroom.

Finally, families need to be encouraged to get involved in community activities, such as church, playgroups, Little League, or ballet classes. These groups

can provide special activities and opportunities for children to exercise skills in coping and integration on a smaller scale than in a full-time classroom. Playgroups can be especially valuable sources of learning and support for everyone involved. Support does not always have to come from professionals or from other parents of children with disabilities. Parents can work out sibling (and other) issues in the company of friends. Children begin to learn about and accept differences as well as how to relate to and communicate with others. Lessons learned through experience, although not always pleasant, are powerful.

Sibling Concerns and Opportunities



Siblings of children with disabilities feel many of the same emotions and concerns that their parents feel.

However, because of the nature of sibling relationships, they also have concerns that differ from those of parents. The sibling relationship is lifelong, frequently the most lasting relationship in the family. Siblings are truly “in for the long haul.” A sibling may never know life apart from a brother or sister with a disability; their world view is, therefore, fundamentally different from that of their parents. To them, the child’s disability may simply

seem to be a fact of life and perhaps puzzling in the disturbance that it causes. The unique nature of sibling relationships forms the foundation of quality sibling support programs.

Children have more limited life experiences than do adults to help put disabilities into perspective. Many children fabricate their own explanations and interpretations for various disabilities and situations; these fabrications are often far from the truth.

A child's sense of identity is closely tied to siblings. Siblings of children with disabilities may experience overidentification, wondering whether they share or will have the disability. Siblings may also feel embarrassment at some point in time, often during adolescence, about their family member's disability. Peers may make fun of people who are different, possibly people who have the same disability as the family member, or they may make fun of the sibling directly. Conversely, siblings may wonder at the phenomenon of their brother (or sister) with a disability being so well known or fussed over; after all, he seems to be just like any other typically annoying brother at home.

Siblings may experience feelings of isolation, loneliness, loss, and resentment, especially during times of stress, such as during hospitalization, diagnosis, or a fair hearing process. Siblings of children with disabilities may feel increased responsibility for their sibling and for the emotional and physical well-being of their parents. They often have questions about the future:

- What will happen to the sibling with the disability?
- Will one sibling need to take care of the other?
- Will the disability be passed on to future children?

On the other hand, many siblings of children with disabilities exhibit positive characteristics that may be attributed to their unique experiences.¹⁰ They are typically more advanced in maturity and show heightened insight and tolerance for diversity. Their advocacy skills are advanced, having had daily opportunities to exercise them or to observe the advocacy efforts of others. Siblings often choose careers in the helping professions, having had the opportunity to observe an array of

¹⁰Carol Russell, Cassie Russell, and Mikelle Russell, "We're Special, Too!" *Disability Solutions*, Vol. 2, No. 3 (1997), 5.



After several heart-wrenching play dates when my young son witnessed his sister being singled out for mistreatment by the five-year-old leader of the group, I watched with pride as he announced to the older child, and everyone else, that that game was “mean,” it was making his sister “sad and mad,” and he was ready to go home! I let him know how proud I was of his support for his sister and we talked about what we all might do when a similar situation arose in the future. We also talked about why his friend might feel the need to treat his sister the way that he did. It was, all in all, an invaluable teachable moment.

—Angela McGuire, Parent

professionals in the fields of medicine, education, and social services.

Sibling support programs help siblings identify and appreciate what is special in themselves and in their family member with a disability. Siblings take pride in the accomplishments of their sibling with a disability; they observe the sibling’s strengths and struggles and share in the celebration of achievement. Additionally, sibling support programs help siblings to identify and deal with their concerns and assist them in finding positive ways to build on the opportunities brought their way.

Effective Sibling Support



Support programs may take various forms, but an understanding of essential principles may help provide effective support.

- ***Siblings will be siblings*** regardless of different abilities. Some situations just naturally occur in any sibling relationship: children fight, brothers may be goofy, and sisters may be bossy. These situations should be accepted as part of life.
- ***Siblings need accurate information***, repeated and updated, to help them fully understand the nature of their

sibling’s disability. Providing information that is out of date will serve only to hamper siblings in their understanding and adjustment.

- ***Information about a child’s disability should be developmentally appropriate when given to siblings***, reflecting the sibling’s maturity. To allow a sibling amplification of information that will be appropriate, reflect back to him or her the question posed.
- ***Sibling support should be offered for an extended period***, allowing siblings to gather information as questions arise and as situations change, such as during times of transition or crisis.
- ***Information conveyed to siblings should agree with parents’ information, understanding, and values***; therefore, two-way communication must be maintained with parents to provide information to them and to obtain it from them.
- ***Follow-up efforts*** to assess the degree the child understands the information and to provide additional information and resources should be a part of all sibling support.
- ***Sibling support should provide opportunities for siblings to participate in***

effective communication. They are given permission to express, understand, and accept their feelings.

- **As family members, siblings should be included in activities relating to special education.** When it is developmentally appropriate and in the best interest of the children, siblings may be invited to participate in IFSP/IEP meetings, special classes, appointments, and therapies. These opportunities can provide firsthand, accurate information about their sibling's disability. Also, siblings' perspectives may contribute to team discussions.

Sibling Support Workshops



One of the most comprehensive forms of sibling support is the sibling workshop, an informal gathering of a group of siblings facilitated by one or more leaders to provide information and an opportunity for sharing. The sibling workshop is a well-documented form of sibling support, thanks primarily to the efforts of Donald Meyer, Patricia Vadasy, and Rebecca Fewell who developed Sibshops.¹¹ Sibshops give information in a recreational setting.

. . . The recreational setting of the Sibshops helps assure that they will be rewarding for the child to attend. If a sibling regards a Sibshop as yet another time demand associated with the handicapped child, he or she may find it hard to be receptive to the information

presented in the workshop. Further, if the Sibshops fail to offer anything that is personally satisfying for the sibling, he or she is unlikely to attend them in the future.¹²

Sibshops promote informal sharing and the development of friendships that can be ongoing sources of support for children. More specific information on setting up a Sibshop is contained in *Sibshops: A Handbook for Implementing Workshops for Siblings of Children with Special Needs*, available from the University of Washington Press and from the Sibling Support Project in Seattle, Washington.

Other Avenues for Sibling Support



Sibling workshops independent of Sibshops have been developed and successfully implemented. Various approaches to sharing information include field trips, parent interviews, and hands-on activities utilizing equipment, simulations, and interaction with professionals. Some programs run sibling and parent workshops simultaneously. Parents may interact with a panel of older siblings to enable them to better understand both the rewarding and the distressing aspects of being a sibling of a child with a disability. Skits are a good way to act out problems and solutions. Some programs have provided direct counseling; others have allowed siblings to spontaneously share feelings and problems to be dealt with by the group leaders and the other group members.¹³

¹¹ Donald J. Meyer, Patricia F. Vadasy, and Rebecca R. Fewell, *Sibshops: A Handbook for Implementing Workshops for Siblings of Children with Special Needs*. Seattle: University of Washington Press, 1985.


¹² Ibid.

¹³ Thomas H. Powell and Peggy Ahranhold Ogle, *Brothers and Sisters: A Special Part of Exceptional Families*. Baltimore: Paul H. Brookes Publishing Co., 1985, pp. 63–68.

Family Resource Centers

I was surprised when my very young son asked me if his sister couldn't talk because she has "germs in her." He had put together what he knew about his sister's struggles with speech and what he'd recently learned about germs, sore throats, and earaches. We took this opportunity to discuss very simple specifics of his sister's disability (her muscles are soft, her tongue is big, she has to work harder to learn), and he was satisfied with what he learned. This information was presented in a way that was developmentally appropriate for his age.

—Angela McGuire, Parent



Family Resource Centers (FRCs) are a statewide, community-based system of parent-to-parent support services. Although individual FRCs in each community vary, they all provide support and information to families and promote positive relationships and joint problem solving between families and professionals. The FRCs support the emotional and informational needs of families and help them obtain services and understand the early intervention service delivery system.

FRCs may help families identify and articulate their strengths, resources, and needs in developing their individualized family service plans (IFSPs). Community agencies, interagency councils, and other organizations work closely with FRCs in promoting public awareness and implementing outreach efforts associated with early intervention services in their community. Professionals and agencies seeking to implement family-focused services look to FRCs as a source of information and support. The FRC staff can provide a family perspective on single- and multi-agency teams and support the inclusion of parents and families as important members of the early intervention services training team.

FRCs are a hub of family involvement. Most FRCs were developed and are managed and staffed by parents of children with disabilities. FRCs link families with families and with a multitude of community agencies, services, and resources.

One of the unique and most valuable services offered by FRCs is parent-to-parent support. The parent support group functions much like any traditional self-help group. "These groups are self-governed, very personal, positive thinking groups that offer individualized humaneness, information, and caring from someone who has been there," explains Florene Poyadue.¹⁵

Parents can effectively help other parents because they have experienced the same problem or situation. A parent of a child with a disability can feel an immediate connection to another parent of a child with a disability. This bond can transcend cultural and socioeconomic differences and allow parents to communicate with each other on an intimate, trusting level about issues of central concern to them even though they have known each other for only a few minutes. Parents respect each other for the challenges they face while understanding that neither of them is a saint and they are each just doing the best that they can for their child. The benefits of parents helping parents are circular. Parents who listen and share their story may be provided a new frame of reference, new strategies for coping, or new encouragement and inspiration every time they talk to another parent.

Increasingly, local educational agency (LEA) professionals appreciate the role and value of FRCs, and FRCs have learned how to meet the needs of LEA professionals while simultaneously

defining and developing their own role in supporting parents. Communities in which professionals have seen the positive impact of FRCs have acknowledged their value and have demonstrated their support by making referrals, sharing resources, and engaging in joint projects. The communities have found that the more they do together, the more they like and respect each other, and the better they achieve their shared goal of supporting parents.

FRCs receive many calls from the community. The following lists indicate typical questions asked by professionals and parents; the roles of FRCs are indicated in parentheses:

Calls from Professionals

- "We need a parent who can talk about the impact that a child with a disability can have on the family. This person will be a member of a panel during Disability Awareness Week. Would you find one for us?" (Community awareness)
- "I'm working with a parent of a child with a very rare disorder. He has frequent seizures and difficulty eating. The mother is feeling really isolated and alone. It might help for her to talk to another parent. Do you know of someone with a similar experience who could talk to her?" (Parent-to-parent support)
- "There's a parent here at the hospital who just had a baby with Down syndrome. We have an interpreter here, but I just don't think the mother understands the special care she's going to need to give the baby. Do you have a parent who could come to the hospital and talk with her?" (Parent-to-parent support)

¹⁵ Florene S. Poyadue, *Steps to Starting . . . A Family Resource Center or a Self-Help Group*. Santa Clara, Calif.: Parents Helping Parents, The Special Children's Family Resource Center, 1991, pp. 5-6.

Calls from Parents

- “Our support group needs a place to meet. Do you have any ideas?” (Resources for support groups)
- “My daughter is 18 months old. She just learned to walk, but she’s still not talking or making any understandable sounds. I’m worried about her. Is there someplace I can take her to find out if there’s something wrong?” (Referral to early intervention services)
- “My son is nine months old and has mild cerebral palsy. He doesn’t qualify for regional center services, but I still think he needs therapy. Do you know of any programs that could help him?” (Information and referral)

Family Resource Centers and Community Agencies

FRCs may collaborate with community agencies to host the following activities:

- Transition Fair
- Toy Fair
- Co-sponsors of community events
- Co-sponsors of family activities and parent education classes through local parks and recreation districts
- Co-sponsors or team participants in Disability Awareness Week activities
- Support of multiagency efforts to build a community playground that is accessible by wheelchair


Family Resource Centers and Professionals

Professionals providing educational, medical, and social services may support the work of FRCs in the following ways:

- Refer parents to FRCs.
- Make other professionals aware of FRCs.
- Volunteer to serve on an FRC advisory board.
- Ask representatives of the FRC to serve on the advisory board of the child care center.
- Invite FRCs to participate in in-service training.
- Participate in FRC-sponsored training.
- Advertise parent involvement activities in FRC newsletters.
- Invite FRC staff to parent involvement activities.
- Ask FRCs to provide parent education workshops for families in their infant or preschool program.
- Provide meeting space for FRC activities.
- Donate printing services for outreach materials produced by FRCs that serve families in the infant or preschool program.
- Donate resources, tapes, books, and information to the FRC library.



Afterword



This handbook provides professionals and parents ideas for developing meaningful family involvement with infant and preschool special education programs. Family involvement consists of more than attending events or activities.

Meaningful family involvement occurs when professionals and parents develop a partnership based on mutual respect and trust to design and deliver services for young children. When this partnership exists, family involvement occurs on a regular basis, and planned activities and events are successful in drawing families together.

The following thoughts express parents' attitude toward the professionals in the parent-professional partnership:

- Your unconditional respect for our families and your view of us as “well” families help us feel competent and give us confidence in our own resources.
- You are going to be an important part of our children's lives. We want to get to know you as people and not just as professionals. Although we are parents of children with disabilities, we are also interested and involved in other things in addition to our child's disability. Together, let us discover the common ground we share.
- Your love and acceptance of our beautiful children help to encourage us and validate our own love and acceptance of them just the way they are.
- In the process of your assessments and evaluations, please acknowledge with us what our children can do. Help us see our child's potential and unfolding

stages of development instead of focusing on deficits and remediation.

- So that we can become effective managers, coordinators and decision makers for our children, it is important for us to see you in the role of consultant as we are learning to coordinate services for our children, write IFSP outcomes, develop goals for an IEP, or go through the process of transition.
- We appreciate your help in identifying and providing opportunities to talk with other parents who have gone through the same things that we are going through. We also appreciate regular reminders that these opportunities are available.
- We are newcomers to the world of disability; you are the teachers, we are the students. You are newcomers to our families; we are the teachers, and you are the students. We must learn together to be an effective support for the children.
- Sometimes when trying desperately to meet the needs of our child with a disability, we overlook the needs of our other children. You, as professionals, can help us remain aware of the special needs of our other children. Together we can identify appropriate support options for them.
- With information about resources and programs that can help our children, we can strategize together on the best plan for services that will maximize our children's potential and at the same time fit in with the needs of our family.

Celebrate our successes with us! We will work as a team to solve problems and come up with solutions.

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